

# It's Not Only Adolescents Who Are Non-Adherent

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# The Case of Child T

- Male infant (Child T) required treatment following birth for posterior urethral valves
- Kidney function deteriorated and subsequent severe infection required chronic dialysis
- Parents relationship unstable – both parents commenced dialysis training but father did not complete
- Child eventually discharged home to mother's care
- Support from renal team and local social work team following discharge

# Concerns about Child T

- Mother's relationship with father continued to be unstable
- Living arrangements problematic
- Mother's social isolation
- Clinic appointments were not kept
- Communication with mother became difficult – phone calls not answered
- Grandparents support questionable – their work commitments came first
- Meeting with family and professionals held to discuss missed appointments

# Evidence that Child T suffered significant harm

- September 2007 – pro-card eventually produced by mother for analysis
- October 2007 – Child T admitted with peritonitis - acute haemodialysis required
- Mother confronted about Child T's poor physical state and evidence of dialysis sessions being missed
  - Mother denied allegations
- Child T referred to social services and name placed on Child Protection Register
- Child T spent 3 months in hospital on haemodialysis – legal proceeding considered
- Mother later admitted non-adherence – Mother re-trained to do PD along with her mother

# Child T's current situation

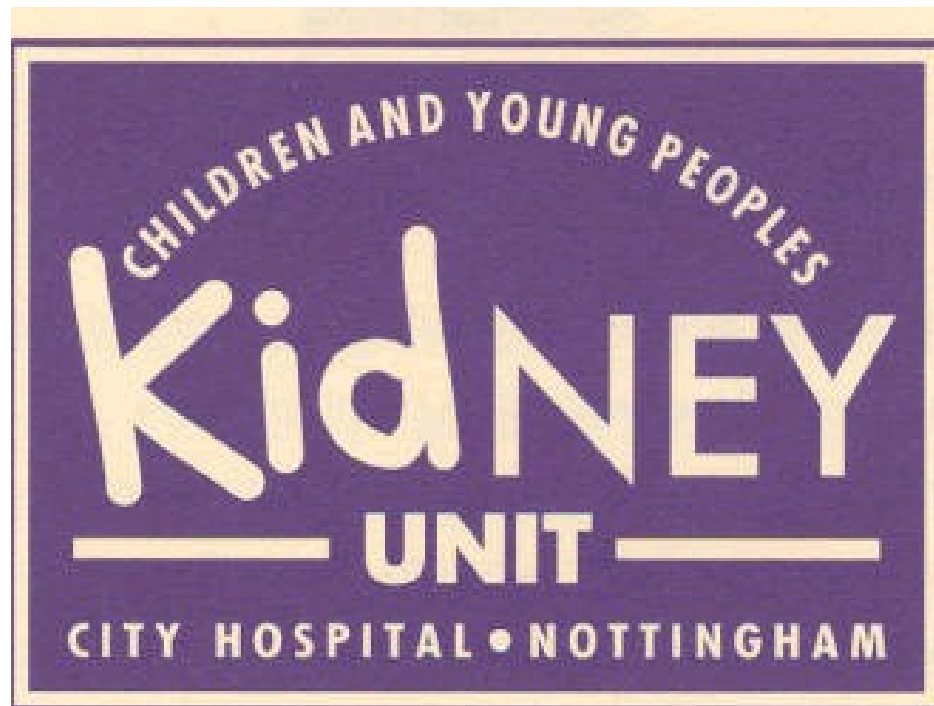
- Child T now living with mother in her own home
- Child Protection Plan involves professionals working with mother to ensure Child T receives PD and thrives
- Maternal grandmother undertakes dialysis twice a week
- Infrequent contact between Child T and father
- Mother still requires support and monitoring and Child T likely to be on child protection register for foreseeable future

# Issues highlighted by case of Child T

- It is well documented in the literature that families with a child on chronic peritoneal dialysis have a significant burden of care (Watson, 1996; de Paula et al., 2008)
- The case of child T is a severe example of non-adherence by a parent
  - Less analysis in the literature regarding younger children compared to teenagers (Faulkenstein et al., 2004)
- In our unit there are other young infants whose care is sub-optimal
- Assessing non adherence by parents very difficult
  - What are the thresholds for intervention?
  - Is the child in imminent danger?
  - When is it neglect?
  - What does intervention involve?

# Practice issues to consider

- Case highlights the importance of on-going psychosocial evaluations of families (Fielding et al., 1999; Furth et al., 2003)
- Parental understanding about expectations for themselves and their child need to be reviewed. Often discrepancies between what health care providers feel they told parents and what they actually recall
- Challenge of educating other agencies about the implications of neglect in early infancy and impact on children with chronic renal failure
- Pressure on renal teams to meet all needs to alleviate burden of care e.g. respite care, escorts to accompany children for haemodialysis



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